



Observatório da Deficiência
e Direitos Humanos

Disability and Human Rights Observatory

PARALLEL REPORT

ABOUT THE MONITORING OF THE RIGHTS

OF PERSONS WITH DISABILITIES

IN PORTUGAL

June 2015

List of subscribing organisations

Members of the Advisory Board of the *Disability and Human Rights Observatory*

Fully Subscribe

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2. Associação dos Deficientes das Forças Armadas (ADFA)
3. Associação Nacional dos Deficientes Sinistrados no Trabalho (ANDST)
4. Associação NOVAMENTE
5. Associação Portuguesa de Hemofilia e de Outras Coagulopatias Congénitas (APH)
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8. Federação das Associações Portuguesas de Paralisia Cerebral (FAPPC)¹
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13. Fundação LIGA
14. Fundação Irene Rolo
15. HUMANITAS (Federação Portuguesa para a Deficiência Mental)⁶
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¹ 19 affiliates

² 53 affiliates

³ 10 affiliates

⁴ 12 affiliates

⁵ 43 affiliates

⁶ 34 affiliates

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17. Associação Portuguesa de Deficientes (APD), with the exception of the paragraph 20.3 and 25.1.

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18. Associação de Famílias Solidárias com a Deficiência (AFSD)
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24. Associação Portuguesa da Síndrome do X Frágil (APSXF)
25. Associação Salvador
26. Associação Sociocultural dos Deficientes de Trás-os-Montes (ASCUDT)
27. BIPP - Inclusão para a Deficiência
28. Centro de Reabilitação e Integração de Deficientes (CRID)
29. Movimento dEficientes Indignados
30. Sociedade Portuguesa de Esclerose Múltipla (SPEM)

Partially Subscribe

31. Associação de Surdos de Évora, with the exception of the paragraph 25.1.
32. Confederação Nacional dos Organismos de Deficientes, with the exception of the paragraph 25.1.⁷

⁷ 38 affiliates

Executive Summary

This report represents the contribution of civil society for monitoring the Convention on the Rights of Persons with Disabilities in Portugal. Prepared in the context of the *Disability and Human Rights Observatory* of the School for Social and Political Sciences / University of Lisbon, the report draws from data collected in a number of studies and involved a broad process of consultation with persons with disabilities and their representative organisations. Both the outcomes of these studies as well as the knowledge gathered from the disability organisations that subscribed the report – a total of **241 disability organisations** - point to a set of areas that are particularly problematic for the human rights of citizens with disability in Portugal. The present report focuses on these issues. The following obstacles stand out as the most significant:

In relation to the equal recognition before the law (article 12 and 14):

- Persons with intellectual and psychosocial disabilities who have been subjected to the regimes of full and partial guardianship are prevented from exercising a number of rights notably in the areas of marriage and family life, political rights, property rights, among others. In addition, the court may determine their compulsory institutionalisation.

In relation to Awareness-raising, Accessibility and Social Participation (articles 8, 9, 19 (a) and (c); 20; 29 e 30):

- Persisting stereotyping and prejudice remain important obstacles to the social participation of persons with disabilities in Portuguese society. Lack of enforcement and non-compliance with the Accessibility Law in place results in lack of access to the physical environment, public roads and transportation, while gaps in existing legislation (that do not covers accessibility to information and communication systems) further erodes rights to social participation. Finally, inclusion as equal members in the community is compromised for persons with disabilities by the absence, in the Portuguese legal framework, of the professional role of personal assistant and the lack of a national policy concerning independent living, as well as by the insufficiency and inadequacy of social care provision in the community.

In relation to Economic Security and Support Services (article 28):

- Very low levels of disability-related benefits provided (between €59,64/month to €293,45/month), excessive bureaucracy and slowness in the process of allocation of assistive devices and insufficiency of the annual public budget spent on these items, and the persistency of a charity approach in the functioning of the public services of social care create significant barriers to the enjoyment of the right to an adequate standard of living and social protection.

In relation to Education (article 24):

- Despite the passage of the Inclusive Education Act in 2008 the implementation of this policy is fraught with a number of problems including: the insufficiency in the quality and quantity of human resources (e.g. therapists, and “special education teachers”) and materials (e.g. books in Braille and other assistive devices) for the promotion of inclusive school; problems with the use of the ICF as the referential tool for needs assessment and planning of the intervention with students with disabilities (e.g. lack of adequate professionals’ training to use the tool, leading to subjectivity and disparities in the assessments); limited participation of families in school life and absence of legislation that enables children and youngsters with disabilities to participate and/ or contest the decisions made in relation to their own education. Moreover, this legislation does not cover postsecondary education and thus students with disabilities in this level of education face additional barriers related to denial of reasonable accommodation⁸ and lack of support services.

In relation to Work and Employment (article 27)

- Since 2009, with the introduction of a new legal framework for the sector, financial and technical supports for the vocational training of persons with disabilities have been decreasing while employers take increased advantage of support mechanisms (e.g. internship programmes), made available by the State to promote employment for vulnerable groups (including persons with disabilities), as a means to supply their workforce without creating new jobs. In parallel, in the public sector, the quota law adopted in 2001, remains poorly enforced. Not surprisingly then, employment rates of

⁸ Within the Portuguese legal framework reasonable accommodation is only foreseen in relation to work and employment (Labour Code (article 84), Law 46/2006 and Decree-law 290/2009).

persons with disabilities are much lower than those found in the general population, as EU-SILC 2012 data clearly shows, while alternative and flexible measures for labour market inclusion lack.

Additionally, the report addresses three cross-cutting issues, namely:

The situation of women and girls with disability (article 6)

- Available data shows that girls and women with disabilities have lower levels of education and employment and lower access to support services than boys and men with disabilities. However, the Portuguese State does not recognize the risk for multiple discrimination faced by women and girls with disability. As such, it fails to provide adequate protection, notably against violence (e.g. insufficient attention to the issue in the National Plan to Fight against Domestic Violence and within disability-specific legislation), as well as in issues related to girls and women's sexual and reproductive rights.

The lack of statistics and data collection (article 31)

- In this area we signal a lack of systematic, updated and disaggregated (e.g. by disability, age, gender, etc.) statistical data about the population with disabilities in Portugal, including data on children with disabilities.

National implementation and monitoring of the Convention (article 33)

- The national implementation of the CRPD has been limited by a number of factors including: the absence of a coherent and integrated strategy for disability at national level, the late and still incomplete establishment of the national mechanism for monitoring the Convention and in general by the limited participation and representation of disability organisations in the design and implementation of disability policy in the country.

Recommendations

Taking into account the obstacles, gaps and problems identified we propose a set of recommendations, for each of the different areas addressed. Thus:

Equal Recognition before the Law

- To change the Portuguese legal framework in order to enable the equal recognition before the law of all persons with disabilities, as stipulated on article 12 of the CRPD and General Comment 1;
- To abolish the existing systems of full and partial guardianship which take away legal capacity and to develop systems of supported decision-making that allow and promote the effective exercise of rights, in accordance with the spirit of the CRPD and General Comment 1;
- To raise awareness in families and throughout society about this issue;
- To review the mental health legislation in order to eliminate the possibility of compulsory internment and strengthening community supports.

Awareness-raising, Accessibility and Social Participation

In relation to Awareness-raising:

- To disseminate information on the rights of persons with disabilities and raise awareness throughout the Portuguese society on disability in order to demystify prejudices and stereotypes, and present persons with disabilities as human beings with equal rights;

In relation to Accessibility:

- To enforce the implementation of the existing Accessibility Law (Decree-law 163/2006);
- To review the Accessibility Law (Decree-law 163/2006) in order to include norms about access to information and communication systems;
- To adopt new editions of the National Plan to Promote Accessibility II (PNPA II) and the National Strategy for Disability II (ENDEF II);
- To pass legislation concerning accessibility in all transportation systems (including public and private, urban and rural, metropolitan, regional and interregional) and to enforce

existing accessibility norms applicable to transportation infrastructure (railway stations, stations and bus stops, etc.);

- To increase the requirements set on private television operators regarding the number of hours broadcasted in an accessible format and increase the number of hours of informative programmes broadcast in accessible format in the public channels;
- To include the topic of accessibility and universal design on the initial training programmes of engineers, architects and urban planners;
- To develop specific regulations to ensure accessibility to the polling stations, including the availability of alternative forms of voting (electronic voting, Braille ballots, among others);
- To regulate and enforce accessibility of information materials in electoral campaigns, such as leaflets, videos, etc.;

In relation to independent living and inclusion in the community:

- To create a new legal framework to support independent living, to establish the professional role of Personal Assistant and implement a pilot-project of Personal Assistance, as it was already foreseen in ENDEF I (the National Strategy for Disability I), while providing for its progressive enlargement and including in this service the provision of Sign Language interpretation services;

Economic Security and Support Services

- To raise awareness and train civil servants (particularly those on front office tasks) to address disability issues and persons with disabilities from a human rights perspective;
- To provide training to and support informal caregivers, so that they can play their role safely and respecting the human rights of the persons with disabilities being cared for;
- To raise the amount of disability-related cash benefits, and to review the eligibility criteria to access them in order to ensure an adequate standard of living;
- To extend the supply of home care services (24h/day), adjusted to the reality of persons with disabilities;
- To expedite and simplify the procedures for the allocation of assistive devices and support products, in order to ensure an effective and cost-free universal system, taking into account the person in its context; also, to increase the support for the maintenance of such products and to introduce control mechanisms to ensure the quality of the allocated products;

- To increase the provision of social care services for persons with disabilities, notably through the creation of group homes.

Education

- To increase the number of mainstreamed reference schools for the education of blind and low sight children, bilingual education schools for deaf students, mainstreamed reference schools for early intervention and for children with multiple disabilities and the number of structured learning units for the education of students with autistic spectrum disorders;
- To reinforce the human and material supports for Inclusive Education;
- In the continuous training of teachers and non-teaching staff to increase the provision of training on disability and inclusive education, namely on its principles as well as on intervention and evaluation strategies; In order to create inclusive schools these topics should receive high priority;
- To include disability issues as mandatory topic in the initial training of all teachers;
- To increase the budget allocated to support education and early intervention with children with disabilities;
- To create a legal framework for the provision of supports to students with disabilities in higher education and remove physical, information and communication barriers in universities, in accordance with existing legislation (Accessibility Law - decree-law 163/2006);
- To raise awareness and educate parents and school communities about disability issues;
- To introduce human rights and disability contents in the curricula of students in primary and secondary education;
- To encourage the recruitment of teachers and other school staff with disabilities in regular schools.

Work and Employment

- To review the framework legislation concerning the measure “employment internships” in order to establish a set of obligations on the part of the employer (notably regarding the creation of new jobs) once the specific financial support is ended;
- To fulfil the employment quotas for persons with disabilities in the public sector;
- To regulate employment quotas in the private sector;

- To increase the use of supported employment mechanisms, facilitating access to the open job market;
- To increase funding and the provision of inclusive vocational training for persons with disabilities and change the respective framework in order to allow greater flexibility in individual training paths (e.g. concerning the number of hours of training), according to the specific needs of each trainee;
- To improve the monitoring and enforcement mechanisms concerning the prohibition of discriminatory practices on the grounds of disability in the workplace;
- To reinforce the complaint and protection mechanisms regarding work-related harassment and violence and to raise awareness about disability issues among employee support structures (e.g. Ombudsman, unions, workers' committees);
- To raise employers' awareness about disability issues and to promote corporate social responsibility concerning the employment of persons with disabilities.

Women and girls with disabilities

- To address the issue of multiple discrimination faced by girls and women with disabilities in the Portuguese legal and policy framework;
- To strengthen research and intervention in order to combat violence against persons with disabilities, namely domestic violence;
- To strengthen policies, programmes and support services related to the promotion of the sexual and reproductive rights of women with disabilities;
- To promote the training of sexual and reproductive health practitioners on disability-related issues.

Statistics and data collection

- To improve the systematic gathering of statistical data on persons with disabilities in Portugal;
- To conduct a nationwide survey on disability;

- To develop a system of disability-rights monitoring indicators in Portugal. All of this should be done with the involvement of persons with disabilities and disabled people's organisations.

Implementation and national monitoring of the CRPD

- To adopt a National Strategy for Disability that clearly states the objectives that will be pursued, the measures that will be undertaken and their indicators, budgets and deadlines, identifying the responsible actors, in order to promote an integrated disability policy that will contribute to the national implementation of the CRPD;
- To increase the participation and representation mechanisms of disabled persons' organisations in the design, implementation and evaluation of disability public policy.

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Introduction

1. This report responds to the challenge set out in article 33 (3) of the Convention on the Rights of Persons with Disabilities referring to the involvement of civil society in the process of disability rights monitoring. In this way, it gives voice to persons with disabilities and their representative organisations providing their views about the implementation of the Convention, at the legislative, administrative and judicial levels and, above all, at the level of daily life experiences of persons with disabilities in Portugal.
2. This document was prepared in the context of the *Disability and Human Rights Observatory*⁹, hosted by the School for Social and Political Sciences / University of Lisbon. The Observatory is an independent organism that brings together researchers and disability organizations, notably through an Advisory Board composed of 18 disability organisations¹⁰, and aims to assess the implementation of disability policies, in Portugal and in the Portuguese speaking countries, promoting participatory monitoring and the full development of the human rights of persons with disabilities.

Methodology

3. Since its foundation, in May 2013, the Observatory has been supporting the development of several studies on the human rights situation of persons with disabilities in Portugal. Among the research conducted, stands out a monitoring study carried out in 2013/14 applying the methodology of *Disability Rights Promotion International*¹¹. This research involved 60 interviews with persons with different disabilities, aged 12 years old and over, living in three different regions of the country (urban, semi-urban and rural). The study also included the collection and critical analysis of legislation using the norms and standards of the Convention as benchmarks and an analysis of the media representations of disability from the study of three Portuguese media outlets, over the last five years. The outcomes of this study largely supported the preparation of the present report, which also draws from research available in Portugal and parents' reports collected by Associação

⁹ <http://oddh.iscsp.utl.pt/index.php/en/>

¹⁰ The Advisory Board of the *Disability and Human Rights Observatory* is composed of 11 organisations and 7 federations, representing all together 182 disability organisations.

¹¹ <http://drpi.research.yorku.ca/>

Pais-em-Rede. The report was developed using an emancipatory¹² methodology, following five stages:

- 3.1. Initial meeting with the disability organisations that are members of the Advisory Board of the Observatory in order to define a working methodology;
 - 3.2. Working session to identify the problematic areas (hot issues) for the exercise of human rights and priority areas of programmatic, policy and legislative action to include in the report (largely based on the outcomes of the DRPI monitoring study, especially the data collected through the individual interviews);
 - 3.3. Discussion about the recommendations and contributions of the organisations and drafting of the report;
 - 3.4. Two working sessions for discussion and approval of the final document.
 - 3.5. Dissemination of the report to all disability organisations in the country and gathering of additional subscribers. This brought the number of signatories of this report to a total of **241 disability organisations**.
4. According to the methodology chosen by the group, the report will focus on the articles of the Convention in relation to which, both the outcomes of the DRPI monitoring study and the knowledge of the signatory organisations pinpointed the most significant barriers for the exercise of the human rights of citizens with disabilities in Portugal. These are: **Equal Recognition before the Law (articles 12 and 14), Awareness-raising, Accessibility and Social Participation (articles 8, 9, 19 (a) and (c); 20, 29; and 30), Access to Support Services and to Social Security (article 28), Education (article 24) and Work and Employment (article 27)**. The report is organized in accordance with these problematic areas, proceeding each time with a description of the current situation of rights and advancing concrete recommendations for amendments or legislative innovation and public action to promote the rights of persons with disabilities in Portugal. This report also addresses cross-cutting issues such as gender discrimination of **Women and Girls with Disabilities (article 6), Statistics and Data Collection (article 31)** and the **National Implementation and Monitoring of the Convention (article 33)**.

¹² The emancipatory research methodology gives a central role to persons with disabilities and their representative organizations in all stages of the research process, including regarding the control of the research agenda and funding. This research aims at creating useful knowledge to fight against discrimination and the social structures which produce and reproduce social inequalities (see for instance Barnes, 2001, available at <http://disability-studies.leeds.ac.uk/files/library/Barnes-glasgow-lecture.pdf>).

Problematic areas for the exercise of Rights and Recommendations

Equal Recognition before the Law (articles 12 and 14)

Current Situation

5. Equal recognition before the law is fundamental for citizens' participation on an equal basis with others, as expressed in the possibility of **exercising the rights** enshrined in both international human rights instruments and the Portuguese Constitution.
6. However, the Portuguese legislation framing the inabilitation and interdiction regimes (hereafter referred to as full and partial guardianship regimes) allows the possibility to limit this exercise to a group of citizens on the grounds of disability, thus clearly opposing what article 12, namely in paragraphs 2 and 3 stipulates. The levelling of these persons to the condition of minors thus results in a generic limitation to the exercise of their rights and perpetuates stereotypes of dependence and inability to decision-making.
7. Therefore, it is necessary to recognize the need to develop alternative forms of support in decision-making processes. This concern is noticeable in the paragraph four of article 12, and also in General Comment 1.
8. Presently, many persons (including elders with neurocognitive diseases) are placed under the full and partial guardianship regimes, taking away their legal capacity to exercise rights and not ensuring the safeguards system which reflects the spirit of paragraph four of article 12 of the Convention and General Comment 1.
9. Placing someone under a regime of full and partial guardianship on the grounds of disability has impacts at various levels, including (among others):
 - 9.1. **Discrimination in the exercise of voting rights.** According to the Electoral Law (Law 14/79, Decree-Law 319-A/76, Organic Law 1/2001), persons with intellectual disabilities that are covered by the full and partial guardianship regime, the so-called "demented" even if not interdicted, and those who are institutionalised in psychiatric institutions are prevented from voting.
 - 9.2. **Impossibility to marry and take on parental rights and responsibilities.** Article 1601^o of the Civil Code determines the impossibility to enter marriage to all those who are "interdicted and inabilitated" due to "psychic anomaly"; these persons are also

unable to exert parental responsibilities (paragraphs 1 of the article 1850 of the Civil Code and paragraph 1b of article 1913^o of the Civil Code).

9.3. Contracts and other trade acts that they enter are void and/or not legally binding.

In accordance with article 125 of the Civil Code, all the acts undertaken by minors that imply the exercise of rights will be considered as void, with the exception of acts regarding the management and disposal of goods that the major of 16 years old has acquired by its own work and those related to the everyday life of the minor. As persons with disabilities who are interdicted are considered equivalent to minors (article 139 of the Civil Code), they are also prevented from signing contracts and entering other trade acts.

9.4. Discrimination in asset and property management. All those who are in a situation of full and partial guardianship are unable to manage their own assets and property (article 1970^o of the Civil Code); this task is placed in the hands of a representative or guardian.

9.5. Possibility of the Court to determine compulsory institutionalisation. According to the Portuguese law, persons with “severe mental health issues” may be limited in their life choices and subjected to compulsory internment. The Mental Health Law (Law 101/1999, from July 26th) determines compulsory internment whenever this is the sole way of assuring that the treatment is effectively followed and to the extent that compulsory internment constitutes a solution proportional to the danger and the legal good at stake.

Recommendations

10. To change the Portuguese legal framework in order to enable the equal recognition before the law of all persons with disabilities, as stipulated on article 12 of the CRPD and General Comment 1;
11. To abolish the existing systems of full and partial guardianship which take away legal capacity and to develop systems of supported decision-making that allow and promote the effective exercise of rights, in accordance with the spirit of the CRPD and General Comment 1;
12. To raise awareness in families and throughout society about this issue;

13. To review the mental health legislation in order to eliminate the possibility of compulsory internment and to strengthening community supports.

Awareness-raising, Accessibility and Social Participation (articles 8, 9, 19 (a) and (c); 20; 29 and 30)

Current Situation

14. From a legal point of view, awareness-raising in the field of disability and the rights to accessibility and social participation are enshrined in Portugal, through both general legislation (i.e. the Constitution) and specific regulations (i.e. the Base Law for the Prevention, Rehabilitation and Integration of Persons with Disabilities and the Accessibility Law). Still, many Portuguese with disabilities are denied these rights on a daily basis. Among the key barriers faced the following are highlighted:

15. In relation to awareness-raising:

- 15.1. **Persistency of attitudinal barriers to disability.** Stereotyping and negative labelling on the grounds of disability sustain individual attitudes and behaviours and institutional practices that limit the opportunities for inclusion and social participation of persons with disabilities in Portugal. In accordance to the disability rights study (Pinto et al., 2014), prejudice and demeaning representations of persons with disabilities remain one of the major obstacles to social inclusion and have a strong impact on quality of life and dignity, feeding feelings of inferiority and devaluation which inhibit social participation, as the following testimony reveals:

I need help to get up, to do my personal hygiene, etc., and people think that someone in that situation doesn't think like someone who does everything by him or herself. People with disabilities are treated as if they were immature, like children, as if they only need to eat, sleep and nothing more. It is the "poor little one" label.

(José¹³, 29 years-old)

¹³ To protect the confidentiality of data, the names used in testimonies are fictitious.

15.2. While legislation exists forbidding and punishing discrimination on the grounds of disability (Law 46/2006), the persistence of such attitudes reveals a lack of information and a lack of awareness on disability issues and the need to promote the rights of persons with disabilities, issues that must be urgently addressed.

16. In relation to Accessibility

16.1. **Lack of access to the physical environment, public roads and transportation, as well as to information and communication systems** - The national accessibility policy, especially with regard to legislation for the built environment and public roads, is currently in a state of stagnation by the blurring of measures concerning the second phase of the National Plan for the Promotion of Accessibility 2012/2020 (PNAP) and the lack of enforcement and non-compliance with the Accessibility Law (Decree-Law 163/2006 from August 8th). In regard to accessibility to information and communication systems, there is a positive development with the approval, in 2014, by the Regulatory Authority for the Media (ERC) of the Multiannual Plan, that foresees measures to ensure access of persons with disabilities to TV broadcasts, through subtitling, Portuguese Sign Language and audio description. However, being an agreement voluntarily established among the main TV channels, there is no enforcement mechanism attached to it. Moreover, a comparative analysis with the previous plan reveals setbacks in the requirements that must be met by private television operators, in terms of the number of broadcast hours in accessible formats up until 2016, a decrease that is only compensated by an increase in the number of hours in one of the public channels (RTP2).

16.2. As a result of the lack of accessibility in the built environment, on public roads and transportation systems, as well as the lack of accessibility to information and communication systems, the life of persons with disabilities in Portugal is strongly limited by experiences of segregation and social isolation (Pinto et al., 2014). The following testimony illustrates some of these difficulties, even in the country's capital:

In the city the sidewalks are either too tall or they have obstacles. Often people are not allowed to walk on the sidewalks, they must walk on the roads, because there are sign posts blocking their way or waste bins or the sidewalks don't have any lowered areas

where I can safely climb or descend the sidewalk. And then, there are some monuments that don't have ramps or accessibility for persons with disabilities. People can't enjoy those spaces. (João, 29 years old)

16.3. Lack of accessibility in voting procedures. The electoral law in Portugal does not foresee alternative ways for persons with disabilities to cast their vote (i.e. through electronic voting or ballot papers in Braille); it only foresees the possibility of the elector to be accompanied by a personal assistant of his/her choice, who exerts the right to vote in his/her place. Even if this system allows blind people to vote, it compromises the right to a free and secret vote. On the other hand, there is no specific regulation to ensure the accessibility of polling stations and in spite of the recommendations made by the National Election Commission, conditions of physical accessibility are not always ensured, which prevents some people with physical impairments from exercising the right to vote. Moreover, the dissemination of information materials in accessible formats during electoral campaigns is scarce since these materials are often made available only in the final stages of the campaigns and are poorly advertised and distributed. The absence of specific regulations guaranteeing the accessibility of this information leads to situations of discrimination in the exercise of free and informed voting.

17. In relation to independent living and inclusion in the community:

17.1. Absence, in the Portuguese legal framework, of the professional role of personal assistant and lack of a national policy concerning independent living, including the absence of Sign Language interpreters in public services (they are only available in the courts, in the Regional Centres of the Institute of Social Security - ISS, IP; and the Employment and Professional Training Institute – IEFP, IP). According to the testimonies of deaf persons collected in the disability rights study monitoring, the absence of interpretation services has an especially severe impact on access to hospital services and health centres, imposing an important barrier to access healthcare (Pinto et al., 2014). While the implementation of a pilot-project of personal assistance was foreseen in the National Disability Strategy 2011-2013, this measure was never put into practice. To date, a new national strategy for disability policy remains to be adopted. This legal and political void, as research has shown

(Pinto, 2011; Portugal, 2010), contributes to perpetuate the dependency of persons with disabilities on their families, placing over them a significant personal, economic and social burden, and creating serious obstacles to the social and economic inclusion of persons with disabilities, as illustrated by the following testimony:

My hygiene tasks take some time and the service does not start until 8h – exceptionally, as a general rule it starts at 9h, but they have opened an exception in my case. Still, I only get to work around 11h and often at 11h30, which causes me great inconvenience. On the other hand, when getting to bed I do not resort to the service because often they finish the service while I'm still at work. Often, they finish at six, making people go to bed at six, seven, eight o'clock. (Afonso, 45 years-old)

17.2. Lack or inadequacy of social care provision in the community. In order to address the growing demand for continued support services without investing in the creation of new community facilities, the Government changed the admission criteria of some services, namely those of nursing homes (where, for lack of suitable alternatives, many adults with disabilities live). A new law was approved in March 2012 (Ordinance 67/2012 from March 21st) that changed the operating rules of these programmes, including the directives related to the minimal dimensions of the rooms in these facilities. As a result, rooms that would previously accommodate two persons may now hold three while individual rooms may now be turned into double rooms. This situation led to an increase in the number of users without increasing the number of available facilities. Clients have lost their privacy and it is likely that the quality of care has diminished (Pinto and Teixeira, 2012). It becomes necessary to review this legislation, in order to provide the supports needed to ensure independent living to all persons with disabilities to allow them to choose where and with whom they want to live. If not, the transition to a new public policy paradigm, in line with the Convention and based on the recognition of the right to social participation of persons with disabilities is strongly compromised.

Recommendations

18. To address the problems, insufficiencies and gaps described above we propose:

19. In relation to Awareness-raising:

19.1. To disseminate information on the rights of persons with disabilities and raise awareness throughout the Portuguese society on disability in order to demystify prejudices and stereotypes and present persons with disabilities as human beings with equal rights;

20. In relation to Accessibility:

20.1. To enforce the implementation of the existing Accessibility Law (Decree-law 163/2006);

20.2. To review the Accessibility Law (Decree-law 163/2006) in order to include norms about access to information and communication systems;

20.3. To adopt new editions of the National Plan to Promote Accessibility II (PNPA II) and the National Strategy for Disability II (ENDEF II);

20.4. To pass legislation concerning accessibility in all transportation systems (including public and private, urban and rural, metropolitan, regional and interregional) and to enforce existing accessibility norms applicable to transportation infrastructure (railway stations, stations and bus stops, etc.);

20.5. To increase the requirements set on private television operators regarding the number of hours broadcasted in an accessible format and increase the number of hours of informative programmes broadcast in accessible format in the public channels;

20.6. To include the topic of accessibility and universal design on the initial training programmes of engineers, architects and urban planners;

20.7. To develop specific regulations to ensure accessibility to the polling stations, including the availability of alternative forms of voting (electronic voting, Braille ballots, among others);

20.8. To regulate and enforce accessibility of information materials in electoral campaigns, such as leaflets, videos, etc.;

21. In relation to independent living and inclusion in the community:

21.1. To create a new legal framework to support independent living, to establish the professional role of Personal Assistant and implement a pilot-project of Personal Assistance, as it was already foreseen in ENDEF I (the National Strategy for Disability I), while providing for its progressive enlargement and including in this service the provision of Sign Language interpretation services.

Economic Security and Support Services (article 28)

Current Situation

22. The Portuguese State provides a set of programmes, benefits and allowances directed at persons with disabilities and their families, which aim to ensure social protection and economic security and compensate the added social risks faced on the grounds of disability. While we acknowledge the importance of these policies, it is nonetheless important to stress the gaps and insufficiencies that remain and which compromise the enjoyment of our human rights and our full social inclusion in society. Among these, the following points must be highlighted:

22.1. **The very low amount of disability-related benefits provided.** These benefits range from €59,64 to €293,45 a month. According to the outcomes of a study conducted in 2010 (Portugal, 2010), social benefits are the main source of income for persons with disabilities and their households due to low educational levels, poor employment rates and lack of support services. Accordingly, the low levels of benefits awarded by the Portuguese State do not adequately protect against the social and economic risks of disability, nor do they allow an adequate level of living. As recent Eurostat data reveals (EUSILC, UDB 2012 – version 2 of August 2014), the risk of poverty among persons with disabilities in Portugal stands at 31,4%, while for the non-disabled population that level stands at 22,8%. In 2010, new and more restrictive eligibility criteria for accessing social benefits were introduced and the level of these benefits is frozen since 2011 (Pinto and Teixeira, 2012). A recent study reveals that households

with a person with disability face additional annual costs that vary from €7.716 to €25.307, amounts that clearly exceed the awarded social benefits (Portugal, 2010), as Table 1 illustrates.

Table 1 - Disability-related Social Benefits: Amounts Provided

| Social Benefits | Amounts Provided |
|--|--|
| Invalidity Pension | Variable amount according to the claimant's contributory career |
| Lifetime Monthly Allowance | €176,76/Month |
| Family Allowance Bonus for Children and Youth with Disabilities | Ranges between €59,48 and €139,15 (depending on the household income and whether it is or not a single-parent household) |
| Special Education Allowance | Up to €293,45/Month during the school year |
| Third Person Assistance Allowance | €88,37/Month |

22.2. Insufficient accessible transportation services and difficulties to access this type of support. Taking into account the lack of accessible transportation in Portugal, many firemen corporations provide a door-to-door transportation service to persons with mobility impairments in their ambulances. This is frequently the only means of transportation available for persons with disabilities when, for instance, they need to attend outpatient rehabilitation services (Pinto and Teixeira, 2012). Still, the legislation introduced in 2011 severely undermined access to this support service, restricting the fee-waiver to “persons with a level of incapacity of 60% or more” and with a family income equal or inferior to €419,22 while requiring, in all instances, a medical prescription¹⁴. The eligibility criteria¹⁵ became more restrictive, limiting the use of this service to 120 days per year, a limit that may only be surpassed in exceptional and duly justified cases (Pinto and Teixeira, 2012). As a result of these restrictions, many persons with disabilities were excluded from this support, with severe consequences in what concerns their access to needed rehabilitation care, as illustrated by the following case.

¹⁴ Decree 142-B/2012

¹⁵ Order 7861/2011

JL is a 20 years old youngster with multiple disabilities, who is a wheelchair user and who, due to the severity of his disabilities needs personalized care 24 hours/ day. JL attends a Centre of Occupational Activities being transported daily to the Centre in an ambulance. Although inadequate (JL does not need to be transported in an ambulance) this service allows him to leave home and to attend daily a day care center to participate in leisure, rehabilitation, art and sports activities. JL lives just outside Lisbon and therefore he is not eligible for the adapted, door-to-door bus of the municipality of Lisbon. In 2012, JL could only benefit from 120 days of transportation service, since his family doctor refused to issue a report that justified an extension of this service. Since his family did not have any other means to ensure his transportation, JL had to stay at home from June to December, being unable to attend the Centre of Occupational Activities by lack of accessible transportation.

22.3. Excessive bureaucracy and lengthy processes of assistive devices allocation and insufficiency of annual budgets for these items, resulting in long waiting periods and unnecessary dependence.

The process of obtaining assistive devices is extremely bureaucratic and slow for the applicants (it can almost take a year), involving various steps: initial medical assessment to obtain a medical prescription, subsequent assessment for determining the impact of the assistive device in daily life of the applicant, obtaining three budgets in the market, before the final decision is taken (Pinto and Teixeira, 2012; Portugal, 2010). A long period of time often elapses from the first assessment until the provision of the device. Often, when the device finally reaches the applicant it is already maladjusted to his/her needs, especially when it comes to children and persons with chronic and degenerative diseases, a situation which translates into increased costs for the State and create barriers to the exercise of the right to adequate social protection.

22.4. The persistence of a charity approach in the way public social care services operate,

which strongly opposes the spirit of the Convention that places persons with disabilities at the centre of decision-making and the design of social care provision, showing that there is an urgent need for training these professionals (Pinto et al., 2014). The following testimony illustrates this reality:

How does a social worker [of a city council service] assign an apartment in a 4th floor to a family that has two wheelchair users? In the 4th floor?! If they have all the files, all the data saying that there are two wheelchair users, how do they assign an apartment on the

*4th floor?! In a building that only has stairs. To reach the building it is necessary to climb a number of stairs, and inside the building there are even more stairs. I'm stuck at home.
When I want to leave, I always need to have someone with me. (Ana, 29 years old)*

Recommendations

23. To address the problems identified above, we recommend:

- 23.1. To raise awareness and train civil servants (particularly those in front office tasks) to address disability issues and persons with disabilities from a human rights perspective;
- 23.2. To provide training to and support caregivers, so that they can play their role safely and respecting the human rights of the person with disabilities being cared for;
- 23.3. To raise the amount of disability-related cash benefits, and to review the eligibility criteria to access them in order to ensure an adequate standard of living.
- 23.4. To extend the supply of home care services (24h/day), adjusted to the reality of persons with disabilities;
- 23.5. To expedite and simplify the procedures for the allocation of assistive devices and support products, in order to ensure an effective and cost-free universal system, taking into account the person in its context; also, to increase the support for the maintenance of such products and to introduce control mechanisms to ensure the quality of the allocated products;
- 23.6. To increase the provision of social care services for persons with disabilities, notably through the creation of group homes.

Education (article 24)

Current Situation

24. The Portuguese State introduced in 2008 legislation about Inclusive Education that promotes the progressive closing of special education schools and the inclusion of practically all children with disabilities in regular schools. In this respect, this legislation follows human rights principles; however its implementation has been fraught with a number of problems compromising seriously the right to education of children and youth with disabilities. We highlight in particular the following gaps:

24.1. Insufficiency in the quality and quantity of human resources and materials for the promotion of inclusive schools. As it is mentioned in a recent document from the National Education Council¹⁶, there is a *“clear mismatch between the normative framework and the real provision of resources, either in quantity or in quality, which are made available for schools and other partner organisations”*. The problems identified refer to:

24.1.1. Late placement of specialized staff in regular schools, long after the beginning of the school year and/ or existence of units with insufficient or no technical support;

24.1.2. Very late provision (sometimes only at the end of the school year) of assistive devices and manuals in alternative formats to students who need them;

24.1.3. Unequal distribution of resources and supports throughout the national territory, with some areas in the country without any provision, creating disparities among students according to residential areas;

24.1.4. Lack of clear criteria for the allocation of financial resources and the allocation of special education teachers to schools and partner entities, by the central departments that are responsible for ‘Special Education’;

24.1.5. Lack of training of teachers and non-teaching staff in regular schools to work with children and youth with disabilities;

¹⁶ Recommendation n.º 1/2014 – Public Policies for Special Education, available at: http://www.cnedu.pt/content/deliberacoes/recomendacoes/Recomendacao_DR_1.pdf

24.1.6. Persistence of labelling and negative stereotyping of disability resulting in disrespectful attitudes by other students in relation to students with disabilities;

24.1.7. Difficulties in the transition to secondary school, especially in the so-called ‘professional’¹⁷ schools which are not well-equipped to work with students with disabilities;

24.1.8. Difficulties with transportation services which cause constraints to the students and their families. Insufficiency of adequate resources leading to situations of discrimination affecting students with disabilities mainstreamed in regular schools, as demonstrated by the following testimony:

Andreia is a 13 years old young girl with cerebral palsy who attends an inclusive school. According to the report collected by the Association PAIS-EM-REDE, during the first week of classes the young girl was not removed from the wheelchair neither was it made available to her the mattress she needs for relaxation. For this reason, the girl’s muscular dystonia got worse and Andreia went on to need medication, as proved by the medical statement presented by her father.

24.2. More restrictive eligibility criteria to access supports. The eligibility criteria introduced by the current legislation to access “special education supports” exclude children whose educational needs are deemed temporary. This situation leaves a considerable number of children and youth without needed supports. Without an adequate support these children may be at risk of developing permanent disabilities (CNE, 2014).

24.3. Problems with the use of the ICF as reference tool for evaluation and planning with students with disabilities. The use of the ICF as reference for the assessment of students has been contested. If the use of ICF as an instrument for classification and organisation of information in relation to “special educational needs” has the intention of creating standardised criteria, in reality a great subjectivity has been noted in the assessments carried out by professional teams along the country, with consequences at the level of supports allocated to the children with disabilities in question (FENPROF, 2010; CNE, 2014). However, another evaluation of the

¹⁷ “Professional” schools are an alternative trajectory for youngsters which after 9 years of schooling want a more practical training as mid-level technicians.

implementation of the Decree-Law 3/2008 of 7 January and specifically of the use of ICF as a reference for the evaluation and planning of the intervention (Ferreira et al., 2010), concluded that the use of ICF has been positive, allowing a more holistic and extensive assessment of the students and a better focus on functionality, although it is recognized that these gains are still poorly reflected in the elaboration of the Individual Educational Plans. The same study concluded then, that difficulties remain concerning procedural aspects in the use of ICF, in part due to insufficient training of professionals in using that tool.

24.4. New forms of segregation of children with disabilities. The new legislation concentrates resources and supports for some groups of children (e.g. blind/low vision and deaf children) in the so-called reference schools. These are mainstreamed, regular schools which have units that are specialised in working with a particular group of children with disabilities. As such, the majority of the other mainstreamed regular schools lack adequate supports to promote the inclusion of these students. As a result, new forms of segregation arise, since this situation forces many students with particular disabilities, mainly those who live in rural areas, to undertake long daily journeys, which keep them away from their communities and family life (Correia, 2010).

24.5. Limited participation of families in school life and absence of legislation that enables children and youth to participate in and/ or contest decisions made regarding their own education. Although foreseen by the legislation, schools do not always promote the involvement of parents in processes related to the referral, evaluation and definition of educational measures directed to their children. As to the involvement of students, no reference is made in the legislation regarding children's abilities to contest the decisions made in relation to their own education (Pinto et al., 2014). In turn, according to the results of the report from the Education National Council, available stimuli for the involvement of parents in the education of their children are insufficient.

24.6. Absence of legislation regarding the provision of reasonable accommodation and support services for students with disabilities in higher education. Despite the existence of a special quota for admission to public universities of students with disabilities, there is no legal regulation about the support that universities must make available for these students. Some universities in the country have already developed

guidelines for teachers and non-teaching staff, have created support offices for students with reduced mobility and/or provided accessible materials and equipment; others, however, have not made available any kind of support, which creates disparities among students and compromises their educational success.

24.7. According to data from EUSILC (2012), the early school dropout rate in Portugal is higher among students with disabilities (35.1%) than among other students (21.4%). The gap between the discourse and the practice, resulting from the lack of material and human resources, prevents the implementation of the Inclusive Education policy, compromises the professional prospects of students with disabilities, leading many of them to return to social care organisations once they complete compulsory education.

Recommendations

25. Given the constraints identified we propose to:

25.1. To increase the number of mainstreamed reference schools for the education of blind and low sight children, bilingual education schools for deaf students, mainstreamed reference schools for early intervention and for children with multiple disabilities and the number of structured learning units for the education of students with autistic spectrum disorders;

25.2. To reinforce the human and material supports for Inclusive Education;

25.3. In the continuous training of teachers and non-teaching staff to increase the provision of training on disability and inclusive education, namely on its principles as well as on intervention and evaluation strategies; In order to create inclusive schools these topics should receive high priority;

25.4. To include disability as a mandatory topic in the initial training of all teachers;

25.5. To increase the budget allocated to support education and early intervention with children with disabilities;

25.6. To create a legal framework for the provision of supports to students with disabilities in higher education and remove physical, information and communication barriers in

universities, in accordance with existing legislation (Accessibility law – decree-law 163/2006);

25.7. To raise awareness and educate parents and school communities about disability issues;

25.8. To introduce human rights and disability contents in the curricula of students in primary and secondary education;

25.9. To encourage the recruitment of teachers and other school staff with disabilities in regular schools.

Work and Employment (article 27)

Current Situation

26. Public policy regarding the employment of persons with disabilities comprises a set of measures aiming to promote their vocational training and access to the labour market. However, according to EU-SILC 2012 data, the employment rates of persons with disabilities in Portugal are significantly lower than those of their peers without disabilities: 45% for men with disabilities in comparison with 71,3% of the male population in general and 40,2% for women with disabilities, instead of the 62,7% that are found among the female population in general. These differences are even higher among the younger groups of the population, such as those in the age group 25-34 years old, where the employment rate of the population with disabilities presents a difference of minus 21,7 percentage points than that of the non-disabled population. The main barriers to the exercise of the right to work for persons with disabilities are:

26.1. Insufficiency of financial and technical supports allocated to the vocational training of persons with disabilities. The framework legislation on vocational training and employment for persons with disabilities in Portugal introduced in 2009 (Decree-Law 290/2009, amended by Law 24/2011, Decree-Law 131/2013 and Decree-law 108/2015) considerably reduced the supports available for vocational training programmes and the total number of eligible hours of training (from 5.800 hours to 2.900 hours, or 3.600 hours, for students who need previous social skills training) having also removed some of the previously available incentives for employees that

hire persons with disabilities. Vocational training programmes in Portugal are co-financed by EU funds and by the Portuguese State through the Institute of Employment and Vocational Training but they are mostly provided by non-profit organisations. The pattern of public funding decrease for this area has been visible since 2009. According to official statistics (IEFP 2012 and 2014) the public expenditure for the vocational training of persons with disabilities suffered, between 2010 and 2013, a negative variation of minus 79,1% (from €77 256 837,64 in 2010 to €16 165 152,53 in 2013) while the number of beneficiaries of the various programmes increased by 37,4%. These figures show a contradictory movement between the decrease of the public expenditure and the increase of the demand which necessarily results in lesser level of support provided individually. The effect of these changes is evident in a case collected for a study on the impact of austerity measures on the rights of persons with disabilities (Pinto and Teixeira, 2012, see box).

Between January 2010 and December 2011, M.C. attended a training to become an administrative assistant, completing a total of 2893 hours of training. When admitted to the vocational training programme M.C. was 25 years old, the compulsory education completed but she had not yet had any professional experience and was attending for the first time a vocational training course. M.C. had a mild intellectual disability and lived with her father and stepmother. During the training she acquired skills in computer and archive. At the final stage of the training she completed an internship in a consulting firm with 317 hours of practical in-service training completed in the areas of archive and support to a database feeding. During this period she always received a positive evaluation and revealed great initiative. However, she also needed to improve the pace of her work and thereby the length of stay at the company increased from 2 to 5 days per week. Both the employer and the trainee wanted to increase the time of training but the period of training of M.C. was running out. At the end, the firm did not hire M.C. because it would still needed some more time to better know her and to ensure that she would be able to perform the tasks as needed.

26.2. In turn, there is a **shortage of alternative and flexible measures for labour market and social inclusion**, adjusted to the diversity of persons with disabilities, specifically to persons with more severe intellectual disabilities, in order to promote the development of individual, person-centered pathways. It is also essential to create, in

the transition period and after compulsory education, alternative measures to the current models of Occupational Activities Centers and vocational training. These alternatives should be more flexible and inclusive and involve the community. As it has been observed in some projects developed by disabled people's organisations, the effective involvement of local administrations, companies and other community organisations is determinant for the creation of community networks to support post-compulsory education, as well as labour market and social inclusion.

26.3. Inadequacies of the employment quota in the public sector. Despite the fact that legislation about employment quota for persons with disabilities is in force since 2001¹⁸, a 2006 study, conducted by the National Institute of Administration showed that there are only about 3000 persons with disabilities in the Portuguese public administration, which is less than 1% of all public servants (Anjos & Rando, 2009). Of these, 40% have disabilities related to cancer diagnosis, which suggests that they were already public servants when they acquired their disability. The study concludes, thus, that the admission of workers with disabilities in the Public Administration sector in Portugal has been residual.

26.4. Harassment and discrimination at work. The Portuguese disability rights monitoring study (Pinto et al., 2014) showed that persons with disabilities face situations of discrimination and inequality at work and do not have their skills recognized. Many of the testimonies collected indicated that persons with disabilities continue to be devaluated and rejected in the labour market, facing harassment and verbal and psychological violence, and that many are precluded from making career progress, are financially exploited (namely, receiving a lower wage than other workers for the same job or being forced to work extra hours without adequate payment) as the following interviewee experienced:

When I was working in advertising I worked 2 months without receiving any payment. My colleagues received their salary and I didn't... People are not stupid, they knew I was there

¹⁸ Decree-Law 29/2001 from 3 February which states that for all recruitment processes in the public sector, involving more than 10 vacancies, a 5% quota should be reserved for persons with disabilities; when recruitment involves between 3 and 10 vacancies, one of them should be allocated to a person with disabilities; and when the recruitment process only involves 1-2 vacancies, the candidate with disabilities, if he/she presents similar qualifications, should be hired preferentially.

and I could hardly go anywhere else. So, they could take me for granted. They paid to my colleagues but they didn't pay me. (Filipe, 30 years old)

26.5. Misuse of support mechanisms by employers. The Portuguese State has made available a set of measures to promote the hiring of persons with disabilities in the open labour market, namely through internship programmes, where the support is increased when the intern is a person with disabilities. However, these measures have not had a sustainable effect on the creation of jobs for persons with disabilities since many employers do not provide employment contracts at the end of the internship, as seen in studies conducted by the Observatory (Pinto et al., 2014). Thus, in most cases, workers are dismissed when the financial incentives to the hiring of disabled persons come to term. Considering the current political and financial situation of the country, where public supports are increasingly scarce, it is important to rethink the rules of allocation of these supports, in such a way to prevent and avoid situations like the one described below:

I was hired to perform a task which I was not sure I would be able to perform due to my speech impairment, which was to be a receptionist. Thank God everything went well. It was a one-year contract sponsored by the Job Center. At the end of that year, and although they had previously showed interest in hiring me, the truth is that they did not. And why didn't they hire me? Not because they didn't like me professionally, but because they thought the internship programme could be extended but that was impossible. After one year the responsibility for paying the salary has to be transferred to the hiring company. "We're very sorry, we liked your work very much but..., If we could still use this method [the internship programme], we would keep you because we need you, but we do not have the financial resources and without that support we cannot keep you. (Matilde, 40 years old)

Recommendations

27. To review the framework legislation concerning the measure "employment internships" in order to establish a set of obligations on the part of the employer (notably regarding the creation of new jobs) once the specific financial support is ended;
28. To fulfil the employment quotas for persons with disabilities in the public sector;
29. To regulate the employment quotas in the private sector;

30. To increase the use of supported employment mechanisms, facilitating access to the open job market;
31. To increase funding and the provision of inclusive vocational training for persons with disabilities and change the respective framework in order to allow greater flexibility in individual training paths (e.g. concerning the number of hours of training), according to the specific needs of each trainee;
32. To improve the monitoring and enforcement mechanisms concerning the prohibition of discriminatory practices on the grounds of disability in the workplace;
33. To reinforce the complaint and protection mechanisms regarding work-related harassment and violence and to raise awareness about disability issues among employee support structures (e.g. Ombudsman, unions, workers' committees);
34. To raise employers' awareness about disability issues and to promote corporate social responsibility concerning the employment of persons with disabilities.

Cross-cutting Issues

Women and Girls with Disabilities (article 6)

Current Situation

35. The legal framework for the protection and promotion of the rights of persons with disabilities has undergone positive changes in recent years, namely with the approval of the Law that prohibits and punishes discrimination on the basis of disability and the Basic Law for Prevention, Rehabilitation and Integration of Persons with Disabilities. However, legal and programmatic gaps persist in relation to gender issues within the field of disability. In relation to these shortcomings, it is important to highlight:

35.1. **The non-recognition in the Portuguese legislation of the risk for multiple discrimination facing women and girls with disabilities.** The gender perspective has been absent from disability legislation and public policy in Portugal. The V Plan for Gender Equality, Citizenship and Non-discrimination 2014-2017 comprises one single measure focused on this issue, which calls for awareness-raising actions. This measure is clearly insufficient. The available data reveal that girls and women with disabilities have lower levels of education and employment than boys and men with disabilities as well as lower access to social support and rehabilitation services (Pinto, 2011; DRPI,

2012). These differences have implications for the well-being, inclusion and social participation of girls and women with disabilities, signalling important inequalities that must be addressed. The table below shows differences in access to social benefits between women and men with disabilities in 2013:

Table 2 - Beneficiaries of Disability-Related Social Benefits by Sex, Year 2013

| Type of Social Benefit | Men | Women |
|--|---------|---------|
| Invalidity Pension | 138 121 | 128 759 |
| Disability Supplement | 51 146 | 32 037 |
| Special Education Allowance | 8 688 | 4 839 |
| Allowance for care provided by a third party | 7 449 | 5 761 |
| Living Allowance | 6 940 | 6 410 |

Source: Social Security Statistics

35.2. Weak protection for violence against women and girls with disabilities. Due to the heightened social and economic vulnerability, girls and women with disabilities are more exposed to gender-based violence than boys and men with disabilities. The lack of attention to the phenomenon of violence against women and girls with disabilities at the public policy level contributes to silencing this reality, facilitating its perpetuation. In the monitoring study carried out by the Observatory (Pinto et al., 2014) of the 31 interviewed women, 16 reported at least one instance of physical, verbal, psychological, sexual or economic violence or abuse (the incidence in the male group was only 6 in 29). The following testimony was one of those collected in the study:

My cousin has been living here for four years ... it seems he's been living here for a lifetime ... he doesn't make a move for anything: he doesn't rent a room, he doesn't find a wife. He said to me: "If I wanted women I could have many, I don't need you at all!" and he used me like one uses an old rag, do you understand me, young lady?

(Sofia, 55 years old)

36. **Poor visibility of issues linked to the sexual and reproductive rights of women with disabilities in the national normative framework.** Sexual and reproductive rights are human rights. However, in the national disability legal and policy framework these rights have received little attention – accessible information on these topics is scarce, there is a lack of training on these issues for technical staff, health professionals, families and persons with disabilities and the services and needed supports to enable girls and women with disabilities to experience an healthy sexual and reproductive life are practically non-existent. While forced sterilisation of women with disabilities is not allowed by the Medical Code of Ethics, except under court decision, the absence of legal regulations and the insufficiency of concrete actions in this domain compromise the exercise of human rights in a fundamental area for human expression and fulfilment.

Recommendations

37. To address the issue of multiple discrimination faced by girls and women with disabilities in the Portuguese legal and policy framework;
38. To strengthen research and intervention in order to combat violence against persons with disabilities, namely domestic violence;
39. To strengthen policies, programmes and support services related to the promotion of the sexual and reproductive rights of women with disabilities;
40. To promote the training of sexual and reproductive health practitioners on disability-related issues.

Statistics and Data Collection (article 31)

Current Situation

41. The National Institute for Rehabilitation (INR) is the official body responsible for collecting data and statistics on disability. In the last two population census (2001 and 2011) some questions about disability were included, which is considered positive. However, there are still important shortcomings in this area, notably:

- 41.1. **Lack of systematic, updated and disaggregated statistical data about the population with disabilities in Portugal.** Disaggregated data on persons with disabilities are not systematically collected in the most important surveys and

national statistics, which makes it difficult to compare persons with and without disabilities. Furthermore, specific data on persons with disabilities are also missing – the first official data collection on persons with disabilities – the National Survey on Impairment, Disability and Disadvantage – was conducted in 1995, and has not been repeated since then.

41.2. Gaps in the statistical data about children with disabilities. There is a lack of data on the situation of children with disabilities. Children under the age of 6 years old were excluded from the 2011 Census questions which aimed at determining limitations in daily life activities. It is urgent to address this gap.

Recommendations

42. To improve the systematic gathering of statistical data on persons with disabilities in Portugal;
43. To conduct a nationwide study on disability;
44. To develop a system of disability-rights monitoring indicators in Portugal. All of this should be done with the involvement of persons with disabilities and disabled people's organisations.

National Implementation and Monitoring of the Convention (article 33)

Current Situation

45. Not having submitted any reservation statement or objection, whether in relation to the Convention or in relation to the Optional Protocol, the Portuguese State, by ratifying the Convention, made a commitment to comply with all its inherent obligations. Within the various obligations, the creation of one or more independent mechanisms to promote, protect and monitor the implementation of the Convention is included. Six years after the ratification of the treaty, some vagueness within this domain remains. Only recently, through the Council of Ministers Resolution 68/2014 of 21 November, the national contact points and the mechanism of national coordination were designated and a national mechanism for monitoring the implementation of the Convention on the Rights of Persons with Disabilities was established. According to the resolution, the monitoring mechanism will be composed of 10 members: representatives of public entities and of civil society

organisations from all areas of disability and an academic expert on the field. However, some representatives have not yet been appointed and therefore the mechanism is not fully in place. In addition, we highlight the following gaps:

45.1. Lack of a coherent and integrated strategy for disability at national level. The National Disability Strategy expired on December 2013. Up to this date, we still lack a new National Strategy. It is urgent to bridge this gap.

45.2. Limited participation and representation of the disability organisations in the implementation of the Convention and in the design and implementation of public policy related to disability for lack of a consistent and enduring formal mechanism of political participation of disability organisations.

Recommendations

46. To adopt a National Strategy for Disability that clearly states the objectives that will be pursued, the measures that will be undertaken and their indicators, budgets and deadlines, identifying the responsible actors, in order to promote an integrated disability policy that will contribute to the national implementation of the CRPD;

47. To increase the participation and representation mechanisms of disabled people's organisations in disability public policy.

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